

HLA & transplantatie : de ontwikkeling van een matchingspraktijk

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SUMMARY

Since the second half of the previous century, organ transplantation has expanded enormously. For the first time in history a transplantation practice emerged. The Eurotransplant Foundation is the center of this transplantation practice for the Netherlands and a number of other European countries. This foundation coordinates the exchange of transplantation organs between affiliated transplantation centers in the Netherlands, Belgium, Luxembourg, Germany, Austria and Slovenia. This book is the account of research into the development of Eurotransplant. The description is aimed at the role of the matching criterion. How did the theory on (and the empirical research into) matching develop? How important was this criterion for the rise of the transplantation practice? Which problems were thought to be solved by founding an organ exchange organization? The research into the development of Eurotransplant was conducted through study of primary information sources. The reason for this is that in this way, more insight can be obtained in local developments in research and clinical practice. This study has been based mainly on the archives at the Blood Bank of the Academic Hospital in Leiden, as well as on the Eurotransplant archives, covering a period until 1970. Through analysis of the primary sources, an attempt is made to give a differentiated opinion on the legitimacy of the matching criterion and the *Eurotransplant Kidney Allocation System* protocol (ETKAS), and of the legitimacy of the Eurotransplant organization as a whole. The framework used for this analysis is derived from the modern Science and Technology Studies (STS). This study agrees with this research tradition. In thematically ordered chapters, a picture is sketched of several largely simultaneously occurring developments. By doing so, an insight is offered into the development processes of scientific knowledge, as well as into the development of complex practices.

Following the introductory chapter in which the research question on the rise of Eurotransplant is laid out, chapter 2 gives a description of a development that starts with a clinical observation in 1958, and leads to the beginning of the development of a leukocyte antigen system. In his 1962 thesis, Van Rood described a general applicable method with which further research can be done on this system. This method however, cannot accomplish mutual comparability of the several local research products. To solve this problem the several parallel developments in leukocyte research in the world are synchronized – as described in chapter 3 – by standardizing one of the variables. In 1965 a Center of Laboratory Testing is created, by inviting several researchers to meet, and to have them type the same leukocyte

antigen samples, with their own techniques and antisera. By using this method, the test results become comparable, the various antisera can now be compared as well. Chapter 4 shows how effort is made to distribute the newly obtained comparability worldwide, or to retranslate it to local research practices. In these processes two mutually dependent groups and approaches can be discerned. The research groups try to standardize the antigen variable, among others by typing panels – determining the antigens of the individual donors – on several places, in analogy with the International Reference Panel in Leiden. The NIH, as a large organization, prefers to standardize the antisera, and to make these available for everybody. The researchers however, have to feed the NIH-Serumbank with the necessary sera. The different objectives of these groups are at odds with each other, which has its repercussions on the collaboration.

Chapter 5 returns to the local, Leiden background of the above mentioned developments; how does the fitting in of knowledge development, and interweaving this with local clinical practices, produce the interconnectedness of typing with the renal transplantation practice in Leiden. A description is given of what happens prior to the first renal transplantation in Leiden, and how the typing of leukocyte antigens is combined with this procedure. Chapter 6 describes several efforts to show the positive influence on the final transplantation outcome of matching. Experimental, retrospective and prospective research methods are used to justify the use of typing as donor selection criterion. The presence of the matching effect is attempted to be proven in different manners. However, on the effect of matching, no consensus is obtained. Chapter 7 reveals why, in spite of the lack of confirmed knowledge, in 1967 a proposal is made to institutionalize the uncertain knowledge. By matching unrelated, deceased donors with renal patients on a waiting list, for many more patients a donor kidney can be made available than without exchange. In part this organization already developed – in a process of co-evolution of medical-technical science and Society – in the preceding decennium, but extending Eurotransplant to a matching practice requires adjustments of original ambitions. This is how Europe is divided in separate regions, and typing is decentralized. In chapter 8 the necessary arrangements and agreements between all the collaborating transplantation centers and typing laboratories are described, in order to have the matching practice function as an apparent internal medical-scientific endeavor. In the second part of chapter 8, some specific examples of public involvement in the matching practice are explicitly shown. The rise of Eurotransplant is no internal scientific affair. In the ninth and final chapter a retrospect is given on the development of Eurotransplant. First the development of the cognitive foundation of the matching practice is described once more. Next, the merger of several medical disciplines is discussed, after which some reflections are given on the medic social development of Eurotransplant. Finally the legitimacy of the matching criterion and of Eurotransplant are considered, and a view of the allocation protocol ETKAS, that Eurotransplant launched in 1996.

Eurotransplant was founded with the expectation that matching for HLA antigens would have a beneficial effect on the survival time of transplanted kidneys. This expectation was fulfilled only to a limited extent. However, Eurotransplant adhered for a long time to matching as the main criterion for kidney allocation. This criterion has played a formal role for a long time, but since the introduction of ETKAS, formal criteria are also more in agreement with the allocation practice that was developed in the late sixties.